

INTRODUCTION

I dreamed of being a mother from an incredibly young age. While some little girls daydream about being a ballerina or becoming president, I wanted a family. I would fantasize about it often with my Barbies and baby dolls, playing house well into my tweens.

When I moved into my first home with my fiancé, my mother dropped off numerous tubs of my childhood belongings in my kitchen. It appeared she had saved everything. In the first tub, I found awkward photos of me in thick glasses with a bowl cut (my mother called it the Dorothy Hamill and said it was darling...it was not), faded second- and third-place ribbons from elementary school track meets, handwritten notes to friends, and countless diaries with little keys. The secrets of my life inside.

“Brody and I are going to get married and have five babies and dogs and horses and live in a big, beautiful house. We will have three girls and two boys. I will be a veterinarian. He will play professional basketball and we will be in love forever. Our life will be perfect.”

I was seven, and it was obvious I had my whole life planned

out. But not once did it occur to me that one of my babies could have a disorder that would prevent him from communicating even the simplest need. Or that his body would grow, but his understanding of safety and independence might not. Nobody thinks it could happen to their child.

But the thought nagged me for years after we learned the diagnosis. What if I had known? What if someone had whispered the secrets of my future in my ear during my pregnancy, as if they had a crystal ball?

"You and your baby are destined for a world different than most. You will call him Cooper, yet the world will call him disabled.

"It will be hard at first. You will experience suffering, struggle, and sadness, but eventually you will overcome it, and catch a glimpse of the unbelievable joy he brings to your world. You will come to understand that in fact, you are the lucky one.

"But the beginning, well, it will nearly break you."

If I had been warned about autism and all it would change, would I have run away crying? Or laughed out loud? I guess I'll never know. I do know that nothing prepared me for the way stress and worry would overshadow a large part of my life for years to come. And I don't know if anything truly could have. It was something that I had to experience for myself.

You may read the first chapters of this book and think it's a sad story. Please keep going. You'll see it is not.

You may also think it's a story about a boy with autism. And while yes, Cooper is certainly the star, it is also the story of me as a mother, finding my way down an unexpected path.

It is the story of mistakes and triumphs—of altered dreams and agonizing hope.

A story of a marital compromise, and sibling rivalry, and the shifting perspective of advocacy, as I tirelessly find new ways to give my nonverbal boy a voice in this world.

In the end, it's about discovering exactly who I was meant to be.

And I owe it all to my son.

ONE

Jamie and I met right after I graduated from college, during an internship I took at a large bank. I had no desire to work in banking, none whatsoever, but I wanted to make money and get my foot in the door somewhere. Spending my time with professional men and women seemed like a logical next step toward adulthood.

I was just coming out of a relationship and not really looking to date anyone. As a woman who always had a boyfriend, for the first time in my life I had the freedom to do whatever I wanted, whenever I wanted. I spent my summer working two jobs and having fun with friends.

Then I met Jamie, five years my senior, and far too serious for me. He was working on a promotion from banker to branch manager and had no time for me. In fact, many years later he would tell me he nicknamed me the “flouncy intern in the short skirt” and ratted me out to our boss for taking long lunches. We were at different places in life, or so I thought. But midway through the summer, we found ourselves together at a softball

tournament, the rest of our coworkers canceling last minute. We decided to make the best of it and ordered a pitcher of beer on the patio of the bar.

He spoke of his future plans, his dreams of owning a little house and a fishing boat, and his close relationship with his family. When he got up after a bit to go catch for his softball team, I was a goner. I don't know if it was the tight white baseball pants, the fact that he was a real grown-up man and different than everyone else I had dated prior, or a combination. I spent the night daydreaming about a future with Jamie.

A year later, on a beautiful fall night, he proposed on one knee. I said yes before he could even finish the words, "Will you marry me?" The next year flew by. We purchased a two-bedroom home in Two Harbors, Minnesota, a tiny city located on Lake Superior, where the average high temperature in the summer was sixty degrees. Neither of us knew anyone there, but Jamie had been promoted to manage two smaller banks up the North Shore, so we decided to make it home. I had said goodbye to my career in banking when I found out how much direct sales was involved and took a position as a marketing coordinator for an assisted-living facility. We spent our time living a rather simple life. Just starting out in our careers, neither of us really made any money, but we didn't know any different. We bought that old fishing boat Jamie had told me about on our first date and spent most of our time outdoors and fixing up our old house. And we planned our wedding.

During this period, I very distinctly remember attending a weekend of premarital counseling at the church we had chosen. The class was centered around topics that a couple might encounter throughout their marriage. The class was led by two pastors, a husband and wife. It seemed completely unnecessary because we were madly in love; our relationship could handle anything, and certainly we didn't need help from some counselor.

We sat around the table, munching on cookies and drinking

punch, while the pastors threw out different scenarios. How would you handle a partner with an addiction? Or a partner who lies. A partner who gambles.

They told stories that seemed ridiculous. One included a wife racking up hundreds of thousands of dollars of credit card debt in secret. In another, a husband drank a case of beer every night on his drive home from work, only to tell his wife he was sober. Jamie and I giggled at some of the stories and gave a side-eye to the rest. We spent much of the time doodling and planning our honeymoon.

It's not that we were rude. We just couldn't believe that we would ever end up like that. We were best friends, young and in love. I was twenty-four and he was twenty-nine. We had planned our life together and wanted the exact same things. A house full of kids, country living, success in our careers, and eventually a cabin on a lake to retire to. It was simple. It was planned and therefore it would happen. Oh, the arrogance of twentysomething kids.

The day dragged on. The final question at the end of the session was, "How would the two of you handle having a child with special needs?" I can still remember one of the pastors asking that question. I can even see him—what he was wearing and how he said it so casually, so matter-of-factly. Like it was a common thing. It is burned in my brain now. The foreshadowing is not lost on me.

I remember thinking, *What a silly question*. That would not happen to us. He went on to briefly talk about the stress of having children, and how a child with special needs intensifies it. I remember not being jarred by the question, not in the slightest. I mean, we were healthy and invincible. We had no special-needs children in our families. In fact, I didn't even know a person with special needs. I also didn't plan to do drugs or drink during my pregnancies, so obviously our babies would be fine. Perfect.

I think we scribbled down on the paper that we'd love that

baby just like any other baby. Because that's what you are supposed to say. Right? We were both good people with huge hearts. And that was that. The class was done, and we were off to live our fairy-tale life, the thought of special needs never crossing our minds again until much later.

On September 13, 2008, Jamie and I were married on the wettest day the North Shore had ever seen in a tiny church on a river. The day started with sunshine and a marching band at 6:00 a.m. Like the rain, the musical serenade was not expected either. But it happened to be the morning of an annual Rollerblade marathon, so we danced our way to breakfast to "The Ants Go Marching" and pretended it was for us.

Hours later it was downpouring. The rain came down sideways and in sheets. One would think as I stood in the window of the church, watching our guests run in under giant umbrellas, that I would have been devastated. But I wasn't. I didn't care at all.

Sweating the small stuff that was out of our control was not in my character. I didn't care that one of my family members stole money out of the card basket I made, or that a member of our wedding party passed out before the ceremony was over, or that my new groom had hit a skunk on the way to the church and smelled a bit funky.

I cared that I was getting married to my best friend, the man who made me laugh like no other and rubbed my feet while we binge-watched seasons of *24* and drank 7 and 7's. While Jamie and I were quite different people, and I have the love language compatibility quiz results to prove it, we had one thing in common. We chose joy and simplicity.

Our wedding was a huge success. I loved every second of it. We danced the night away until 2:00 a.m. with our friends and family and went to bed happy and married. But the next morning, after our friends and family were gone and we were alone in our living room, surrounded by gifts, I burst into tears. My new husband didn't know what to do. Instead of feeling

happy, I felt depressed. There had been so much buildup, from the parties to the showers to the constant planning, and then it was just over. I felt like a whole phase of my life had just ended.

As I sat there, I thought back to holidays and big events with my mom over the years, and how she always cried when they were over, and how I never understood why. In that moment I did. She loved the anticipation, the planning, and the buildup. Just like I did.

I turned my excitement to babies after our wedding. We had gone off birth control the month before, neither of us knowing how fast it would happen. We got pregnant the first time we tried, shortly after our wedding. We were surprised by how easy it was. We saw a heartbeat at eight weeks. A little flicker on the screen. We told everyone and immediately announced it on Facebook.

At thirteen weeks, I started to get the feeling that something was wrong. It was the Sunday of Christmas weekend, and the day before a routine doctor's appointment and an ultrasound. We spent the day at my father's house. I was a wreck, sensing that something was just a bit off. I couldn't put my finger on anything specific, just that I no longer felt pregnant. A friend told me that was normal and that symptoms can fade in the second trimester. Google told me it was not really all that normal. The word that came up was *miscarriage*. A word that hadn't crossed my mind.

That evening, Jamie and I went for a walk in the woods with our dogs, a normal evening pastime for our little family. I broke down and cried about halfway through. I told my husband my fear. I was fairly sure something was wrong with the baby. He told me it would be fine. But to Jamie, everything always was fine. He was unshakable.

The next morning, we were crammed into a tiny little room at my OB's office for my twelve-week ultrasound, one week late. This was a big appointment, and Jamie's first time being

in an ultrasound room. I was in a crinkly gown, legs up in stirrups, with Jamie standing next to me, holding my hand. The tech first put the sticky gel on my stomach, moving the device in a slow circular motion.

After just a second, the tech turned the screen away from us, excused herself, and left the room. In her absence, Jamie and I waited in silence. She came back minutes later and said she was going to do a transvaginal ultrasound. As she pulled the big wand out, rolling the condom-like sheath down the shaft, Jamie burst out laughing. “Where is THAT going?” I was thankful for his humor.

After a minute she removed herself from the room again. In that instant I knew. I had read enough horror stories the night before to know what was coming. Our doctor entered after what felt like an eternity and said there was no heartbeat. The baby was gone. Just like that. No real niceties. No small talk first. He did not beat around the bush. My worry was confirmed. I had my answer.

He too called it a miscarriage. He said it is the body’s way of discarding pregnancies that are not viable and attempted to provide comfort to me by telling me that something was wrong with our baby and this was the body’s way of telling us that. “You are not alone. Ten to twenty percent of pregnancies end in miscarriage. It’s quite common.” I’m not sure if that was supposed to make me feel less alone, but it didn’t.

The doctor went on to scribble a picture on a prescription pad. It looked like chicken scratch when he turned it around for us to see. Side by side, drawn close together, were two large circles. Each large circle had a different size smaller circle inside, one visibly larger. Jamie and I still to this day talk about that picture.

“See.” He pointed to the picture and said, “Your baby looks like this one, but it should look like this one at twelve weeks.”

I viewed it through tear-filled eyes. I didn’t see it. I immediately thought of that episode of *Friends*, when Jennifer Aniston

doesn't see her baby on the ultrasound but nods in agreement anyways. He patted me on the shoulder and told us we could try again in a few months, almost like a coach pats his player. He also told us we could have the drawing.

But that wasn't the worst memory of that day. Jamie had to leave. He had to get to a loan closing at one of the banks he managed. He couldn't miss it, and while it was not his fault, I was crushed. I had to wait by myself and schedule the appointment that would remove from my body the baby I had wanted so badly.

As I sat with the scheduler, going over the details of what a D&C was and how the surgery was performed, my tears fell fast and hot. She said I would need to report to the surgery center at five o'clock the next morning and to make sure not to eat after midnight that night. My head snapped up.

"Wait. What? Tomorrow morning? Shouldn't we wait to see if this is wrong?" It was all happening too fast. Shouldn't I get a second opinion? What if the dates were wrong?

She didn't say anything, just made a sad little sound. She then handed me the card with the appointment date and time written on it. Her face said it all.

I had to drive myself home. I left a sobbing message for my boss and for my mom and then turned my phone off. I didn't want to hear that miscarriage was common. I didn't want to hear that we could try again in a few months. I wanted to be sad. I spent the rest of the day trying to figure out how I was going to tell people that I was no longer pregnant, angry at myself for announcing so early. Every scenario felt sad and awkward.

When Jamie returned from work that evening, he found me curled up on the couch. He repeated what our doctor had said. "We could try again. This was a good thing. Something must have been wrong with our baby. Next time it will be perfect."

We arrived at the hospital the next morning for the procedure. The surgery itself was fast. When I woke up in recovery,

still groggy from anesthesia, I asked the nurse if my baby was gone. I drifted back to my anesthesia haze before she could answer, but I do have this memory of her saying out loud, maybe to another nurse, that it was one of the saddest questions she'd ever been asked post-surgery.

I cried for weeks after losing that baby. For the first time I felt a huge loss of control over my own life. I turned to diet, exercise, running mostly, and figuring out why my body had failed me. I dove into research and read about other women who suffered from a miscarriage. I needed to educate myself, but even more than that, I needed to make a connection to others who understood what I was going through. The women I virtually met after my miscarriage would go on to become lifelong friends, that loss bonding us. Finding others who understood was life-changing.

Jamie didn't grieve like I did, and after talking to other women, I guess that's normal for husbands. My body went through something monumental and I wanted to talk about it, but he did not. I was angry that he wasn't sad enough over the loss of our baby, and I suppose he would have said I was too sad. We did not have many fights during our first year of marriage, but we fought hard about our grief over losing that child.

I became hyperfocused on getting pregnant again, almost as if it was a job. Sex became planned and not at all fun. I peed on ovulation sticks in a bathroom stall at work, crying when I didn't get the smiley face. A coworker said to me, "Travel, enjoy this time together. You'll have babies before you know it." She wasn't wrong, but her brazen attitude offended me.

Some time later, after dramatically convincing myself we would never have children, I got a positive pregnancy test. Yet instead of excitement, I felt fear. I didn't want to fall in love with another baby, only to lose him or her.

I left the test on the bathroom sink before hopping on the treadmill in the basement to run. When Jamie got home shortly

after, I asked him to grab me a hair tie in the bathroom. He came downstairs carrying the test, with the biggest grin on his face. “Is this real?” He was so excited. We didn’t say a word to anyone until we were twenty weeks along. Not even to our parents.

Around six months, I finally calmed down and let myself enjoy my pregnancy, and I found out that once I relaxed, I loved being pregnant. Jamie was excited too and even purchased a baseball bat and glove for his first son. When they arrived in the mail, I cried. Jamie’s relationship with his dad was unlike any I had ever known before. They were best friends, speaking daily on the phone. His dad had coached him through many years of sports and was his biggest fan. I had no doubt that Jamie would have the same relationship with our son.

Cooper was born on December 6, after what felt like the longest pregnancy ever. When you have a child diagnosed with special needs, you will forever be asked about your pregnancy and birth. Every therapy center, school, even county you live in will want to know about those nine months. I always found it to be invasive, checking boxes about my vaginal birth on a school form. But the answers stayed the same. Besides gaining way too much weight, my pregnancy was perfect. No issues whatsoever.

The beginning of the birthing process was rather uneventful and slow-moving as well, although the excitement over meeting Cooper and becoming a mother was almost more than I could handle. Because of the baby’s potential size, and lack of movement as I neared forty weeks, my doctor scheduled me for an induction. Jamie and I arrived at the hospital on a Sunday night, and the process was started with Cervidil. No progress. The next morning, I was hooked up to Pitocin. No progress. After hours of walking up and down the hallways, finally there was progress but not enough. While we were ready to meet our baby, he was not ready to meet us. It appeared that we were on his timeline, which was excellent foreshadowing, if you ask me. He wasn’t going to budge for any of us.

Finally, after being in the hospital for twenty-four hours, it was time to push. I felt excitement as the nurse modified the bed, dimmed the lights, and instructed my husband to grab a leg. His face turned white as he looked down. If he could have run away in that moment, he might have. I don't think he was prepared for such an up-close and personal experience.

During the birthing class about labor, I had foolishly assumed pushing came natural to a first-time mother. Like it would be instinctual. It was not for me. I felt awkward and exposed. And after a rather uncomfortable fecal situation, which my husband assured me was nothing, but would tease me about for years to come, I felt discouraged.

Two hours later we had progress. His head had crowned but he was stuck. I was exhausted and didn't know how much more I could take. After all that work, I was nervous my doctor was going to mention the word *C-section*, but instead he used the word *episiotomy*. That did the trick, and I felt immediate relief.

Cooper was born seconds later.

I thought for sure the doctor would place him on my chest right away so I could bond with him immediately like I had seen in the movies, but instead he was passed backward to a waiting nurse without even a glimpse for me. Within seconds, multiple people surrounded him.

I kept waiting for the cry. Everyone talks about that first cry, how it pierces the room. But our room was silent beyond the murmurs from the group surrounding Cooper.

The doctor kept repeating, "He's okay." But I was thinking, how did he know? He was working on me, stitching me up. He was not even looking at the baby on the table behind him. I reminded myself of the old airplane, flight attendant scenario. When you are on a plane, going through turbulence, there is no reason to panic until the flight attendants do. If they sit down and buckle up, well, hang on. The doctor was my flight attendant. He wasn't panicking.

I kept wiggling my butt around, trying to see what the nurses were doing. My doctor told me to hold still, but I couldn't. Finally, I heard a few words and phrases coming from the whispering nurses.

"Intubate. Not breathing right. Come on, baby. Breathe."

It felt like an eternity. In reality it was probably minutes.

"I want my baby. I want my mom. Jamie, get my mom."

And then the piercing, angry cry filled the room. It was Cooper. He was here. Just a little late to the party. And with that I collapsed back against the bed, my arms exhausted from holding myself up, trying to get to my baby. I let out the breath I didn't know I had been holding.

As the nurse set the bundle in my arms, she said, "Congratulations, mama. He's beautiful. And big! You have a nine-pounder here."

I looked down, and finally saw my baby. After all that hard work, and the scare, I had him, and I wasn't letting go. One of my girlfriends had told me the second you have your baby in your arms, the pain of childbirth disappears. She told me the beautiful stories of her daughters' births, claiming she didn't feel an ounce of pain after. I was the opposite. The second I had him, I felt every ounce of pain. He had put me through the wringer. But I didn't care. It didn't matter anymore. I had never loved something more.

The nurse informed us that his Apgar score was exceptionally low, but he seemed to be perking up, so they would just monitor him closely and he wouldn't have to visit the NICU. He did look a little bit like he'd been through hell. His head was cone-shaped and bruised, his blond hair matted down with blood. But what I remember the most were his eyes. I always assumed babies come out sleepy. Not our Cooper. He was wide-awake, eyes open, looking around the room. They seemed to be darting, almost, as if he was trying to make sense of what had just happened. He looked confused. Lost.

Finally, the room cleared out, and as the nurse closed the door behind her, I heard my mom say, "Is everything okay?" She responded with, "Yes, they just need a minute." She was right. We did.

Silence filled the room. Jamie and I finally looked at each other. "Were you scared? Oh my God, I was so scared."

"Naw, I knew it would be alright."

Once again, his calmness amazed me. He seemed unrattled, even unfazed by what had just happened. I, on the other hand, was still shaking.

I looked down again, unwrapping the blanket from the baby in my arms. We counted his fingers and toes. I giggled at the softness of his skin. Jamie kneeled at the side of the bed and placed his finger in our son's hand.

"Hey, Cooper, it's your mama and daddy!" Suddenly I felt my peace. I had my baby. I fell in love immediately and all at once. I was a goner. Images of baseball games and a little boy catching his first fish flashed before my eyes.

People ask me all the time when I realized something was different about my baby. Typically, the questions come from moms of toddlers who have concerns about their own child's development, and they want to be reassured that their child is fine. That it is not autism. I remind them that every story is unique, no two the same.

Some parents speak of a perfectly developing baby and then the flip of a switch at twelve months, the light seeming to dull. Or their toddler is speaking full sentences only to stop overnight. I've had countless videos shared with me...toddlers saying *mama* and *truck* and *ball*, the parents heartbroken over what used to be and is no more. Some parents claim they knew it was autism from day one, while some never saw it coming.

For me, I don't remember a time it wasn't autism. I might not have known the definition of the word yet, or the seriousness of the diagnosis, but looking back, I knew that my baby was autistic from the second I held him in my arms when he was just

minutes old. Autism was woven through him, completing him, like an intricate quilt, unable to be separated out. Even though over the years to come I would desperately pray for it to be. I would try to determine what parts were my little boy and what parts were autism until I eventually realized they were one and the same. Removing the diagnosis would mean removing all of him, a realization that would take me years to accept.

There was a time in our lives when Jamie and I found the very question of raising a special-needs child unimaginable—ridiculous, even. Yet here we were, thrust into a life we were both wholly unprepared for, one that would challenge us, and change us, as a couple and as parents.

Tan pants and a denim shirt. That's what the pastor wore.

Copyright © 2022 by Kate Swenson